What effect does transition to adulthood have on health and wellbeing in young people with intellectual disabilities? A systematic review

Young-Southward, G., Philo, C., Cooper-S-A.

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Abstract

Background

Transition to adulthood might be a risk period for poor health in people with intellectual disabilities. However, we could find no synthesis of evidence on health and wellbeing outcomes during transition in this population. This review aimed to answer this question.

Method

PRISMA/MOOSE guidelines were followed. Search terms were defined, electronic searches of six databases were conducted, reference lists and key journals were reviewed and grey literature was searched. Papers were selected based on clear inclusion criteria. Data was extracted from the selected papers, and their quality was systematically reviewed. The review was prospectively registered on PROSPERO: CRD42015016905.

Results

15,985 articles were extracted; of these 17 met the inclusion criteria. The results of these articles were mixed but suggested the presence of some health and wellbeing issues in this population during transition to adulthood, including obesity and sexual health issues.

Conclusion

This review reveals a gap in the literature on transition and health, and points to the need for future work in this area.

Introduction

Transition refers to the move from childhood to adulthood in terms of service provision, a restructuring of daytime activity, and more holistically in the sense of attaining increased independence and performance across a range of adult roles. While some authors (eg Wyn & Dwyer, 2000) regard transition as specifically referring to the move from school to work, others (eg King et al., 2005) view it as a more gradual process, in which young people develop the skills required for adulthood. In this way transition can be regarded as a prolonged period spanning much of adolescence and early adulthood, including the years approaching leaving school and the period of extended exploration after school exit. Arnett (2000) suggests this occurs between the ages of 18 and 25 and describes it as 'emerging adulthood' (2000:469). Transition is defined in this review as the process of moving from childhood to adulthood, occurring between the ages of 13 and 24 years. This age range incorporates the period before school exit, which occurs in the UK between the ages of 16 and 18, and the period of 'emerging adulthood' described by Arnett (2000).

For young people with intellectual disabilities, achieving social and characteristic markers of independence may be difficult and, in

some cases, unrealistic. Depending on the severity of disability, some young people may not be able to make all of their decisions independently, and may not achieve some goals typically associated with adulthood, such as engaging in an intimate relationship.

A range of poor transition outcomes for individuals with intellectual disabilities have been described in the literature, including social relationships (Hamilton et al., 2015), employment, and independent living (Luftig & Muthert, 2005). There is less focus in the literature, however, on health and wellbeing outcomes for young people with intellectual disabilities during and after transition.

Health status in adults with intellectual disabilities is poor relative to the population without intellectual disabilities (Tracy & McDonald, 2015). Emerson (2011) cites a range of vulnerabilities that contribute to this health inequality, including inherent biological and psychological vulnerabilities, as well as social inequalities such as economic disadvantage, poor health literacy and lifestyle risk factors. Such factors might be more likely to take effect during the transition period. When a young person finishes school they may leave behind a wealth of support and information, including education about maintaining a healthy lifestyle and access to multiple supports that contribute towards positive health and wellbeing outcomes, such as physical or speech therapy. Individuals with intellectual disabilities may also have limited options for meaningful daytime activity once they leave school: Scotland's Census (2011) indicated that only 4% of individuals with intellectual

disabilities in Scotland aged 16-24 were in paid employment fulltime, 5.6% were in paid employment part time, and 39.9% were students (Scottish Learning Disabilities Observatory, 2016).

This lack of daytime activity, coupled with decreased opportunities for social contact upon exiting school (Hamilton et al., 2015), might result in less opportunities to engage in physical activity and a more sedentary lifestyle. A combination of these factors may conspire to result in poor physical health outcomes for young people during and following the transition from school to adult life.

Transition may also impact upon mental health and wellbeing, as leaving school and entering adult life constitutes a vast change in a young person's life. Leaving behind the structure and routine of school might trigger mental health issues, such as anxiety and depression, especially if a young person has no daytime activity to replace the school routine, as is more likely to be the case for those with intellectual disabilities. Expectations to fulfil adult roles – or, indeed, in the case of individuals with intellectual disabilities, possibly a *lack* of expectations – might cause problems within families, which might also contribute to poor mental health outcomes. Negotiating new adult roles and adjusting to changing dynamics within the family and peer group may be a stressful and isolating experience, particularly if, due to cognitive deficits or social stigma, a young person is rendered unable to fulfil their envisaged adult roles. This situation may conceivably result in a particularly difficult period emotionally and psychologically.

In this population, transition also incorporates moving from paediatric to adult health and social services, which may pose challenges. Reiss et al. (2005) cite differing philosophies and poor inter-agency communication and collaboration as contributing to difficult moves, and there is evidence (eg Hudson, 2006) that transition planning is often confusing for young people and their families and ineffective in achieving established goals. This difficult move might also contribute to increased health problems during transition as moving away from the long-term support of child services to an unfamiliar team may be stressful for both young people and their families, and may result in health problems going unidentified.

Transition may therefore be experienced differently by young people with intellectual disabilities from those without disabilities; consequently, transition may have a negative impact on health status in this population. Foley et al. (2012) conducted a systematic review of the literature examining transition for young adults with intellectual disability using the International Classification of Functioning and Health (ICF) as a guiding framework, finding significant gaps in the literature. Robertson et al. (2015) recently conducted a systematic review of systematic reviews on health and health care of people with intellectual disabilities to identify gaps in the evidence base. They found no review examining transition and health in this population. Transition is a crucial period in young adults' lives, and may be a period of vulnerability for young people with intellectual disabilities. This study therefore sought to

systematically review evidence of the impact of transition on health and wellbeing in this population. The research question was 'What effect does transition have on health and wellbeing in young people with intellectual disabilities?' We hypothesise that transition negatively impacts upon the health and wellbeing of young people with intellectual disabilities.

Methods

Both Preferred Reporting Items for Systematic Reviews and Meta-Analyses and Meta-Analysis Of Observational Studies in Epidemiology (PRISMA/MOOSE) guidelines were followed. The review was registered on the international prospective register of systematic reviews (PROSPERO).

Electronic searches of six databases were conducted: Embase (Ovid; 1947 - 2016), Medline (Ovid; 1946 – February 2016), ASSIA (1987 - 2016), ERIC (1966 – 2014), PsycINFO (1887 – 2016) and CINAHL (1981 - 2016). The final search was conducted on 19th January 2016. The searches were undertaken by the lead author under the supervision of the second and third author, and with librarian advice. Key word searches utilising the following terms, including historic terms, were performed:

1. Mental AND (handicap* OR disab* OR difficult* OR impairment OR deficien* OR incapacit* OR delay OR problem OR subaverage)

2. (Intellectual OR learning OR developmental OR neurodevelopmental OR cognitive) AND (handicap* OR disab* OR difficult* OR impairment OR deficien* OR incapacit* OR delay OR problem OR subaverage)
3. (Intellectual OR learning OR developmental OR neurodevelopmental OR cognitive) AND (disorder OR condition)
4. Subnormal OR feebleminded OR imbecile OR idiot OR moron OR oligophreni* OR aphreni* OR defective OR retard*
5. Transition* OR "school to work" OR "child* to adult*" OR "child* to adolescence" OR "life changes"
6. (Mental OR psych* AND health) OR health* OR wellbeing OR anxiety OR worry OR stress OR depress* OR emotion* OR mood OR "common mental disorders" OR "challenging behaviour" OR "complex needs" OR p?ediatric OR hospital OR respite OR "sensory impairment" OR deaf OR blind OR sight OR vision OR hearing OR mobilit* OR "cerebral palsy" OR "down's syndrome" OR autism OR epilepsy OR respiration OR incontinence OR pain OR welfare

Additionally, grey literature, including the UK Health Technology Assessment (HTA) and National Institute for Health and Care Excellence (NICE) clinical, public health and social care guidelines were hand searched. Key word searches, including 'transition', 'school to work' and 'child to adult', in relevant journals (Journal of Applied Research in Developmental Disabilities, Research in

Developmental Disabilities, Journal of Intellectual Disability Research; American Journal on Intellectual and Developmental Disabilities; Journal of Intellectual Disabilities; Journal of Intellectual and Developmental Disability) were also performed. Reference sections of articles were hand searched to ensure that no relevant articles had been missed.

Articles were selected on the basis of meeting the following inclusion criteria:

1. The age of participants was within the range 13-24 years. For articles with a wider age range, results were separately reported for ages 13-24 years or more than 50% of participants were aged 13-24 years old.
2. Participants had intellectual disabilities. Where papers included both participants with and without intellectual disability, data for participants with intellectual disability were reported separately from those without intellectual disability.
3. Both transition and health or wellbeing were discussed.
4. English language.

Studies were therefore included if they covered transition and health or wellbeing, even if they were not designed to be explicitly about transition. All study methodologies were included. Where it was unclear if studies met inclusion criteria, authors were to be contacted. A random sample of 10% of the titles retrieved and of the abstracts that were deemed to be potentially relevant were

reviewed by the third author to check agreement. Differences were planned to be resolved through discussion with all three authors.

Data was extracted from selected studies. The quality of selected studies was systematically assessed using the Critical Appraisal Skills Program (CASP) tools, such as the Qualitative Checklist (2014) for the qualitative studies. They each include 10 items, from statement of aims, methodology, design, participants, study size, measures, data collection, analysis, results, bias, generalisability, value, relationship with researcher, ethics. Each item is scored either 0 or 1, with a score out of 10 indicating the overall assessed quality.

Results

The search produced a total of 15,985 articles (*Figure 1*). 165 duplicates were removed and 15,281 titles were excluded as they were clearly not relevant, leaving 539 abstracts. There were differences in agreement on only 6 titles and 2 abstracts; consensus was reached (to be over-inclusive), and none of these articles were retained at the final stage.

Those abstracts that clearly did not meet the inclusion criteria were excluded, leaving 73 articles which were read in full, yielding a total of 14 articles that met the inclusion criteria. A search of the reference sections of all selected articles and journals yielded 2 more articles, neither of which referred to transition in the title or abstract, and a dataset from the National Longitudinal Transition Study - 2 (NLTS2) (2003), leaving the final number of articles/dataset

for inclusion at 17 (*Figure 1*). We did not need to contact any authors.

Given the large variety of study designs, it was not possible to conduct a meta-analysis. Therefore, a narrative synthesis of the findings was conducted. The evidence reviewed suggests the transition experience may have a negative effect on health and wellbeing overall; however, this evidence is in places contradictory, and the articles reviewed yielded few common themes (*Table 1*). Furthermore, most studies were assessed as having limitations.

Insert table 1: summary of articles, about here

Physical health

Three studies examined physical health outcomes (Rurangirwa et al., 2006; Rimmer et al., 2010; Bhaumik et al., 2011) through a web survey (Rimmer et al., 2010) and questionnaires (Rurangirwa et al., 2006; Bhaumik et al., 2011).

Parents of adolescents with autism or Down syndrome were 2-3 times more likely than parents of young people without disabilities to report that their child was obese or suffered from obesity-related secondary conditions, including diabetes and depression (Rimmer et al., 2010). Access to health education and services was limited, with individuals with intellectual disabilities aged 21-25 at a higher risk of not receiving sex education or pelvic exams than their non-disabled peers (Rurangirwa et al., 2006). While these studies obtained data from parents' reports, the NLTS2 surveyed both young people and

their parents, obtaining ratings of young people's health from both perspectives and finding a disparity between the two.

Mental health

Five studies examined mental health (Hepper & Garralda, 2001; Yu et al., 2008; Taylor & Selzter, 2010; Bhaumik et al., 2011; Barron et al., 2013) through questionnaires and interviews.

A high frequency of emotional and behavioural problems was identified in this population: 86% of a sample of young people with intellectual disabilities aged 16-19 years identified from community services reported physical problems, emotional or behavioural problems, or epilepsy (Bhaumik et al. 2011), and 23 out of 27 young people with intellectual disabilities aged 16-18 had a mental health disorder, with emotional disorder the most prevalent diagnosis (Barron et al., 2013). While persisting into adulthood, mental health problems did not seem to worsen following transition from school: Hepper and Garralda (2001) found a high frequency of emotional or behavioural difficulties among individuals in their final year of school, but found no change in psychiatric morbidity six months after school exit.

Improvements in the autism behavioural phenotype in people with co-morbid autism spectrum disorder and intellectual disability continued to be slow before and after transition from high school (Taylor & Seltzer, 2010). Substance use was also considered but was

not indicated as being problematic for this population in comparison to the non-disabled population (Yu et al., 2008).

Wellbeing

Quality of life was the primary outcome measure for four studies (Kraemer et al., 2003; McIntyre et al., 2004; Davies & Beamish, 2009, and Biggs & Carter, 2016). 64% of parents of children with intellectual disabilities and high support needs in their early twenties described their child as having 'a great deal' or 'much' life satisfaction (Davies & Beamish, 2009). However, parent reports of wellbeing were significantly lower for young people with autism or intellectual disabilities than for a normative sample across the domains of physical wellbeing, psychological wellbeing and social support (Biggs & Carter, 2016).

Themes reported as contributing to quality of life by mothers of young people with severe intellectual disabilities included having basic needs met, having social contacts and vocational opportunities, and health (McIntyre et al., 2004). Young people with intellectual disabilities who were out of school reported higher quality of life than those in school, and those working in the community had higher quality of life scores than those in sheltered workshops (Kraemer et al., 2003). The NLTS2 (2003) considered wellbeing more generally; asking participants how many times health or emotional problems had recently caused them to miss school or social activities. More than half reported that this had 'never happened'.

Relationships and sexual health

Six studies examined relationships and sexual health (Chamberlain et al., 1984; Rurangirwa et al., 2006; Forte et al., 2011; Pownall et al., 2011; Larkin et al., 2012; Young et al., 2016). Methodologies in these studies were primarily qualitative, including semi-structured interviews (Chamberlain et al., 1984; Forte et al., 2011; Pownall et al., 2011; Larkin et al., 2012 and Young et al., 2016) and questionnaires (Rurangirwa et al., 2006).

Social concerns and their effects on mental health were revealed to be of concern, with young people with intellectual disabilities experiencing higher rates of interpersonal conflict and violence than their non-disabled peers (Rurangirwa et al., 2006; Larkin et al., 2012) and reporting being worried about social issues, such as being bullied and making friends (Forte et al., 2011; Young et al., 2016). Young people with intellectual disabilities ruminated more about these worries and were more distressed by them than a control group without intellectual disabilities (Forte et al., 2011) and were significantly more anxious than their non-disabled peers (Young et al., 2016).

Sexual health was revealed as a key issue, both in terms of practical considerations, such as fertility control and menstrual hygiene in girls (Chamberlain et al., 1984), and in psychosocial considerations, such as discussing appropriate sexual behaviour with parents and opportunities to develop independence and form romantic or sexual relationships (Pownall et al., 2011).

Summary of results

The studies reviewed reveal data related to a number of specific physical health concerns, yet there is no comprehensive picture of physical health for this population during and following transition; for example, information on a variety of crucial factors, such as diet, exercise, oral hygiene, or ongoing health problems, is lacking. The studies reveal a more comprehensive picture of mental health and wellbeing outcomes, including relationships and quality of life, for young people with intellectual disabilities; however, more detailed data exploring the ways in which transition impacts mental health and wellbeing, including mood and life satisfaction, is absent.

Discussion

We have found evidence that the experience of transition may have a negative impact on health and wellbeing in young people with intellectual disabilities, with obesity, sexual health and social conflict being three areas of concern. This finding is in contrast to the experience of transition in young people without intellectual disabilities; of the 6 studies included in this review that included a non-disabled comparison group (Rurangirwa et al., 2006; Rimmer et al., 2010; Pownall et al., 2011; Larkin et al., 2012; Biggs & Carter, 2016; Young et al., 2016), the majority found no significant cause for concern in the non-disabled groups, and, in cases where there were negative findings for those without intellectual disabilities (eg Young et al., 2016) those with intellectual disabilities fared worse.

The most striking finding of the review overall is the limited quantity of research on this important topic. Given the large variability in study designs and outcome variables, the findings from this review are somewhat inconclusive. While most parents describe their child's quality of life as good following transition (Kraemer et al., 2003; McIntyre et al., 2004; Davies and Beamish, 2009), those authors who sought the views of intellectually disabled young people themselves uncovered a less positive vision, with high levels of interpersonal conflict and violence experienced (Rurangirwa et al., 2006; Larkin et al., 2012) and worries about social relationships prevalent (Forte et al., 2011; Young et al., 2016). Sexual relationships were also potentially of concern, with sexual health being a key issue for this population during transition (Chamberlain et al., 1984; Pownall et al., 2011). This is concerning given Rurangirwa's (2006) finding regarding the higher risk of limited access to sex education and pelvic exams in this population. With regards to physical health, obesity (Rimmer et al., 2010) was a key issue for this population during this period. While there are obvious physical health implications following from both of these issues, such as unwanted pregnancy and sexually transmitted diseases in the former, and secondary conditions including diabetes, high blood pressure and high cholesterol in the latter, the implications of these issues for emotional wellbeing must also be considered; notably self-esteem, depression and anxiety.

With regards to mental health, Hepper and Garralda (2001), Bhaumik et al. (2011), and Barron et al. (2013) support the notion

that mental health in this population is poor in general, but problems, although continuing from childhood into adulthood, do not appear to worsen following transition. This finding is consistent with previous epidemiological studies, which have found high rates of behavioural and emotional disturbance from young childhood into adulthood in this population (eg Einfeld et al., 2006).

Bias in the samples

There are some key limitations to the studies included in this review. None fully addressed all areas assessed in the quality review. The majority (n=12) utilised parents' perspectives of health and wellbeing outcomes during and following transition for their children; this not only neglects a crucial component of research in this area - the voices of young people with intellectual disabilities themselves - but also introduces a potential bias into the findings. Davies and Beamish (2009) comment on this issue, arguing that, due to their likely large degree of involvement in their children's lives, parents of children with intellectual disabilities are in an informed position from which to comment on their child's experiences. However, in this context, parents may be likely to describe their child's quality of life positively as in many cases they assume responsibility for providing care and may therefore be likely to appraise it as good. The NLTS2 (2003) dataset illustrates this problem: there are differences between parent ratings and self-ratings of general health status among the young people in this cohort, which calls attention to the fact that parents and their

children may be likely to appraise the young person's health differently. McIntyre et al. (2004) conclude that proxy reports for individuals with intellectual disabilities are acceptable for objective but not subjective measures, and the subjective nature of some issues relating to health and wellbeing in the context of transition may present a problem in these studies. Of those studies that did utilise young people with intellectual disabilities as participants, all sought views from those with mild to moderate, rather than more severe, disabilities (n=5). While this is a necessity due to the methodologies utilised in some studies as, for instance, participants must have the capacity to understand and respond to an interview, this also means that conclusions may not be relevant for people with more severe disabilities.

The issue of functional status confounding results is also present in studies where the level of participants' intellectual disability was not reported (n=6). For example, Kraemer et al. (2003) report on scores on quality of life subscales such as empowerment/independence and social connectedness/inclusion, noting that individuals in community employment scored more highly on these scales than individuals in sheltered work placements or in no employment at all. As individuals in community employment might be expected to be more highly functioning than those not in employment, their scores might reflect their functional status rather than their employment status. As intellectual disabilities cover such a large spectrum of ability, it is crucial that the level of disability is reported in order to provide a cohesive picture of research findings.

Recruitment methods utilised in the studies may also affect the results. The majority of studies in this review (n=14) obtained participants from an administrative sample, such as special education schools, and a large proportion (n=5) recruited participants from a single source. Although the methodological advantages of this sampling method are obvious in that intellectual disabilities constitutes a very particular population who might not otherwise be reached, recruiting participants from a single source is problematic in that any data obtained is only representative of those who come from that particular source, and cannot necessarily be generalised to a larger population. For example, Chamberlain et al. (1984) note that, as they recruited participants solely from a clinic that specifically provided family planning among their services, their data may be biased in that they likely over-represent young women who were specifically in need of family planning services. Furthermore, biases are also potentially present in terms of self-selection in the samples.

In addition to these potential biases, only 6 studies included a non-disabled comparison group (Rurangirwa et al., 2006; Rimmer et al., 2010; Pownall et al., 2011; Larkin et al., 2012; Biggs & Carter, 2016; Young et al., 2016). Given the notion that transition is a universal phenomenon (Hudson, 2006), this is an important limitation of the studies included, in that it is vital to accurately assess the differential impact that transition has on those with an intellectual disability compared to those without, in order to adequately inform future care, supports and policy.

Temporal and contextual factors

It is important to consider the time period in which the studies included in this review were published; the date of publication of these studies ranges from 1984 to 2016, and time-relevant factors, such as societal attitudes, may have affected the findings. For example, in a descriptive survey of caregivers' perceptions of sexual behaviours of individuals with intellectual disabilities, Swango-Wilson (2008) found that the younger the caregiver, the more accepting their perception of sexual behaviours of individuals with intellectual disability. This finding might reflect more permissive societal attitudes over time, with younger caregivers being more exposed to and accepting of such attitudes. As this review has highlighted, factors such as sexuality have crucial implications for wellbeing during transition, and wider societal influences on these factors must be taken into account.

In addition, the national setting in which the research took place must also be considered; the studies included in this review are all from the USA, UK or Australia, and while these are all Western countries with presumably similar cultural values, subtle differences, which could potentially impact findings, may be apparent. For example, the USA has a large population originating from central and South America, and there are cultural differences in the demarcation of transition amongst such families, who, in contrast to some Western values, may consider prolonged residence within the parental home as normal and desirable (Rueda et al., 2005).

Therefore, more research is required from cultures besides those included in this review, in order to identify cross cultural differences in the effect of transition on health and wellbeing.

On a similar note, an exploration of the institutional context from which participants were recruited is relevant, as different contexts may place different emphasis on various aspects of wellbeing. For example, educational settings may place more emphasis on vocational outcomes, while mental health settings are more likely to focus on aspects of behaviour and emotion.

Limitations

A limitation of our review is that we excluded studies that were not published in English, which may have introduced publication bias. Furthermore, all studies reviewed were from high income countries. As all of the authors are based in the UK, which has a substantial welfare system, we may be influenced in our interpretation of the studies included in this review through comparing study findings with expectations to individuals with intellectual disabilities also benefitting from state welfare. We may also be influenced through comparing findings with expectations to the general population without intellectual disabilities in high income countries. Finally, only a small number of studies were included in the review.

Conclusions

This review has identified a mixed picture of health and wellbeing outcomes for young people with intellectual disabilities following

transition. While parents tend to report positively on their child's quality of life during transition, there is evidence of some health issues, alongside negative experiences during transition that it is reasonable to assume could result in poor health and wellbeing outcomes for young adults in this population.

Given the overall lack of clear evidence on the impact of transition on health and wellbeing, there is a need for future research to improve on this area. A mixed methods approach, utilising a coherent sampling strategy from more than one source is indicated, including secondary analysis of existing data, such as the NLTS2 (2003) dataset, alongside in-depth qualitative interviews with young people with intellectual disabilities and questionnaires assessing a range of physical and mental health and wellbeing outcomes. A longitudinal study, following a cohort of young people before, during and after transition is also indicated. Such methods are necessary to provide a coherent picture of the impact of transition on health and wellbeing in young people with intellectual disabilities, and to point to any additional supports that might be needed.

References

Arnett, J. (2000) Emerging adulthood: a theory of development from the late teens through the twenties. *American Psychologist* 55 469-480

Barron, D.A., Molosankwe, I., Romeo, R., Hassiotis, A. (2013) Urban adolescents with intellectual disability and challenging behaviour: costs and characteristics during transition to adulthood. *Health and Social Care in the Community* 21 283 – 292

Bhaumik, S., Watson, J., Barrett, M., Raju, B., Burton, T., Forte, J. (2011) Transition for teenagers with intellectual disability: carers' perspectives. *Journal of Policy and Practice in Intellectual Disabilities* 8 53 – 61

Biggs, E., Carter, E. (2016) Quality of life for transition age youth for autism or intellectual disability. *Journal of Autism and Developmental Disorders* 46 190 - 204

Chamberlain, A., Rauh, J., Passer, A., McGrath, M., Burket, R. (1984) Issues in fertility control of mentally retarded female adolescents: I. Sexual activity, sexual abuse and contraception. *Pediatrics* 73 445-450

Davies, M.D. and Beamish, W. (2009) Transition from school for young adults with disability: parental perspectives on 'life as an adjustment'. *Journal of Intellectual and Developmental Disability* 34 248-257

Dyke, P., Bourke, J., Llewallyn, G., Leonard, H. (2013) The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life. *Journal of Intellectual and Developmental Disability* 38 149-162

Einfeld, S.L., Piccinin, A.M., MacKinnon, A., Hofer, S.M., Taffe, J., Gray, K.M., Bontempo, D.E., Hoffman, L.R., Parmenter, T., Tonge, B.J. (2006) Psychopathology in young people with intellectual disability. *The Journal of the American Medical Association* 296 1981-1989

Emerson, E. (2011) Health status and health risks of the hidden majority of adults with intellectual disabilities. *Intellectual and Developmental Disabilities* 49 155-165

Foley, K-R., Dyke, P., Girdler, S., Bourke, J., Leonard, H. (2012) Young adults with intellectual disability transitioning from school to post-school: A literature review framed within the ICF. *Disability and Rehabilitation* 34 1747 - 1764

Forte, M., Jahoda, A., Dagnan, D. (2011) An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood. *British Journal of Clinical Psychology* 50 398-411

Hamilton, A., Mazzucchelli, T.G., Matthew, R. (2015) Parental and practitioner perspectives on raising an adolescent with a disability: a focus group study. *Disability and Rehabilitation* 37 1664-1673

Hepper, F., Garralda, M.E. (2001) Psychiatric adjustment to leaving school in adolescents with intellectual disability: a pilot study. *Journal of Intellectual Disability Research* 45 521-525

Hudson, B. (2006) Making and missing connections: learning disability services and the transition from adolescence to adulthood. *Disability and Society* 21 47-60

King, G.A., Baldwin, P.J., Currie, M., Evans, J. (2005) Planning successful transitions from school to adult roles for youth with disabilities. *Children's Health Care* 34 195-216

Kraemer, B.R., McIntyre, L.L., Blacher, J., Taylor, S.J. (2003) Quality of life for young adults with mental retardation during transition. *Mental Retardation* 41 250-262

Larkin, P., Jahoda, A., MacMahon, K., Pert, C. (2012) Interpersonal sources of conflict in young people with and without mild to moderate intellectual disabilities at transition from adolescence to adulthood. *Journal of Applied Research in Intellectual Disabilities* 25 29-38

Luftig, R.L. and Muthert, D. (2005) Patterns of employment and independent living of adult graduates with learning disabilities and mental retardation of an inclusionary high school vocational program. *Research in Developmental Disabilities* 26 317-325

McIntyre, L.L., Kramer, B.R., Blacher, J., Simmerman, S. (2004) Quality of life for young adults with severe intellectual disability: mothers' thoughts and reflections. *Journal of Intellectual and Developmental Disability* 29 131-146

National Longitudinal Transition Study 2. (2003). NLTS2 data tables Retrieved from http://www.nlts2.org on 16/03/15

Pownall, J.D., Jahoda, A., Hastings, R., Kerr, L. (2011) Sexual understanding and development of young people with intellectual disabilities: mothers' perspectives of within-family context. *American Journal of Intellectual and Developmental Disabilities* 116 205-219

Reiss, J.G., Gibson, R.W., Walker, L.R. (2005) Healthcare transition: Youth, family and provider perspectives. *Pediatrics* 115 112-120

Rimmer, J.H., Yamaki, K., Davis Lowry, B.M., Wong, E., Vogel, L.C. (2010) Obesity and obesity-related secondary conditions in adolescents with intellectual/developmental disabilities. *Journal of Intellectual Disability Research* 54 787-794

Robertson, J., Hatton, C., Baines, S., Emerson, E. (2015) Systematic reviews of the health or health care of people with intellectual disabilities: A systematic review to identify gaps in the evidence base. *Journal of Applied Research in Intellectual Disabilities* 28 455-523

Rurangirwa, J., Van Naarden Braun, K., Schendel, D., Yeargin-Allsopp, M. (2006) Healthy behaviours and lifestyles in young adults with a history of developmental disabilities. *Research in Developmental Disabilities* 27 381 – 399

Rueda, R., Monzo, L., Shapiro, J., Gomez, J., Blacher, J. (2005) Cultural models of transition: Latina mothers of young adults with developmental disabilities. *Exceptional Children* 71 404-414

Scottish Learning Disabilities Observatory (2016). Retrieved from https://www.sldo.ac.uk/ on 19/05/16

Sitlington, P.L., Frank, A.R. (1993) Dropouts with learning disabilities: What happens to them as young adults? *Learning Disabilities, Research and Practice* 8 244-252

Swango-Wilson, A. (2008) Caregiver perception of sexual behaviours of individuals with intellectual disability. *Sexuality and Disability* 26 75-81

Taylor, J.L., Seltzer, M.M. (2010) Changes in the autism behavioural phenotype during the transition to adulthood. *Journal of Autism and Developmental Disorders* 40 1431-1446

Tracy, J. and McDonald, R. (2015) Health and Disability: Partnerships in Health care. *Journal of Applied Research in Intellectual Disabilities* 28 22-32

Wyn, J., and Dwyer, P. (2000) New patterns of youth transition in education. *International Social Sciences Journal* 52 147-159

Yu, J., Huong, T., Newman, L. (2008) Substance use among young adults with disabilities: Facts from NLTS2. *National Center for Education Research* 13 1 - 13

Young, R., Dagnan, D., Jahoda, A. (2016) Leaving school: a comparison of the worries held by adolescents with and without intellectual disabilities. *Journal of Intellectual Disability Research* 60 9 – 2

Authors/ Year	Location	Participants (n, age, sampling, level of ID)	Study type	Study aims	Measures	Findings	Limitations and assessed quality score
Chamberlain et al. 1984	Ohio, USA	N=87 11-23 years old Mild ID N=41; Moderate ID N=23; Severe ID N=23 Drawn from a single multiservice clinic providing adolescent healthcare including gynaecology and family planning N= 69 Mothers of these females with ID	Cross-sectional	To examine issues in fertility control of young women with intellectual disability	Patient chart data from 87 females reviewed 69 mothers completed questionnaires and interviews	Mothers reported difficulty teaching daughters menstrual hygiene (for 88% of daughters with severe ID; 41% moderate ID; 27% mild) 51% females with mild ID, 30% moderate and 9% severe had had sexual intercourse at least once 22 females had known history of sexual assault (14 mild ID; 6 moderate and 2 severe) and 9 of these were victims of incest. 7 pregnancies reported among 6 females. 42 females had used contraception but medical and psychosocial problems complicated their choice of method	Obtained information about sexual intercourse through physical evidence/treatments for STIs so may have underestimated amount of sexual intercourse Potentially biased sample as the clinic specifically dealt with family planning No comparison group 6
Hepper, & Garralda, 2001	London, United Kingdom	N=10 Age 16 Moderate ID Final year of a single special school Recruited through letters from author/department head	Mixed methods Prospective cohort study Parental questionnaire at 2 time points, 6 months apart	To investigate psychiatric morbidity increases at transition from school to adult education/services	Semi-structured questionnaire to parents (child's social functioning, emotional/behavioural problems, contact with psychological services) SDQ	High frequency of emotional/behavioural difficulties prior to transition but no increase/decrease in psychiatric morbidity 6 months after leaving school (median SDQ score = 14 at Time 1 and 14.5 at Time 2)	Small sample and taken from a single school No comparison group Limited time scale (6 months) Initial measure taken at final term of school – could reflect anticipatory anxiety Self-selected sample

							(those who responded to letters) 10 out of 15 sets of parents participated in full study 6
Kraemer et al. 2003	California, USA	N=188 Age 18-26 Moderate – severe ID Drawn from Regional Centre System in California (provide case management to individuals with ID)	Cross-sectional	To examine the quality of life of young adults with ID during transition	Postal survey: Family Data Sheet Vineland structured interview SIB-R Problem Behaviour Scale Family Impact Questionnaire QRS-F F-COPES Support (informal questionnaire) Parent Involvement in Transition Planning (questionnaire) Transition Experiences Survey (interview) QoL-Q	Young people who had exited high school (N=85) had significantly higher quality of life scores (Mean = 76.3) and empowerment/independence subscale scores (Mean = 18.5) than those still in school (N=103) (Mean total QoL = 71.6; mean empowerment = 16.5). Young people working in the community had significantly higher quality of life scores (Mean = 85.2) and competence/productivity scores (Mean = 21.1), empowerment/independence (Mean = 20.1) and social belonging/community integration (Mean = 20.9) subscales than those working in sheltered workshops (Mean total QoL = 75.3; mean competence = 15.0; mean empowerment = 17.1; mean social belonging = 19.7) or not working at all (Mean total QoL = 73.4; mean competence = 11.9; mean empowerment = 19.5; mean social belonging = 18.2) Those in community work did not have higher subjective quality of life scores (satisfaction) than those in sheltered	Parents completed majority of questionnaires – proxy reporting Findings could be related to functioning – higher functioning more likely to be able to keep community work No comparison group 9

						workshops or not working at all	
NLTS2 (SRI International) 2003	Across USA	N = >11,000 of whom ~ 1,000 had learning disabilities at first wave of data collection Age 13- 16 at first wave of data collection Sample drawn from USA special schools, weighted to be nationally representative	Longitudinal cohort, with five waves of data collection spanning 8 years	To document the experiences of a national sample of special education students as they moved from secondary school into adult roles	Parent/student phone interview or postal questionnaire Student assessment – short versions of WJ-III; SIB-R Purpose-designed Teacher Survey Purpose-designed School Program Survey Purpose-designed School Characteristic Survey	24.3% parents rated their child with ID's general health as 'excellent' and 12.7% parents rated 'fair or poor' 28.2% young people with ID rated their own health as 'excellent' and 12.8% rated 'fair or poor' 54.9% young people with ID reported health or emotional problems 'never' causing them to miss school/social activities in previous month 14.9% reported health or emotional problems causing them to miss school 'once a week' in the previous month	Level of ID not reported Data are weighted estimates of respondents nationally N not reported No non-disabled comparison group 6
McIntyre et al. 2004	California., USA	N=30 Mothers of youth with severe ID Age 18-24 Recruited through Southern California Regional Centres (provide case management services to individuals with ID)	Mixed methods Qualitative interview and questionnaire	To examine quality of life of young people with severe ID from carers' perspectives	QoL-Q Semi-structured interview	Most mothers reported child had good quality of life (mean score = 71.6) Themes identified affecting quality of life: activities, having basic needs met, social contact, happiness, health, family life, vocational opportunities, emotional/behavioural problems	Proxy reporting No comparison group 7
Rurangirwa et al. 2006	Atlanta, USA	N with DD = 482 N with isolated ID = 128 N with ID and coexisting	Cross-sectional	To measure leading health indicators (physical activity, obesity, tobacco use,	Structured questionnaire administered face	Young adults with ID had a 6-fold increased risk for not receiving sex education in school or by parents	Responses given by proxies excluded, so responses are biased

		impairment (eg cerebral palsy or epilepsy) = 35 Mild ID N = 132 Severe ID N = 32 Age 21 – 25 Part of the MADDS and MADDS-FU cohorts Recruited via record review Comparison group with no disability N = 124 Recruited from public school rosters		substance use, responsible sexual behaviour, injury and violence, access to health care) in young adults with and without a history of developmental disabilities	to face or via telephone	compared with adults without ID Young adults with ID had a 7-fold increased risk for having been attacked or beaten in the last 12 months Young women with ID had a 9-fold increased risk for never having a Pap smear or pelvic exam	towards those with mild ID ID diagnosed in original MADDS study when individuals were age 10 8
Yu et al. 2008	Across USA	N=2,640 Age 18-21 Random sample of students receiving special education from rosters of LEAs and state-supported schools	Cross-sectional	To provide national picture of prevalence rates of smoking, alcohol and illegal drug use in young adults with disabilities	Telephone interview and postal survey for those who couldn't be reached by phone Questionnaire on substance use – asked to report frequency of use in last 30 days	Young people with ID less likely than the general population to report smoking, drinking or marijuana use. Cocaine use same as general population Young people with ID more likely than those from other disability categories to report smoking, drinking and marijuana use	Response rate 67% Statistics are weighted estimates of national population of youth in this age group receiving special education Level of ID not reported N participants with ID not reported No non-disabled comparison group 6
Davies & Beamish 2009	Queensland, Australia	N=218 Parents of children (early 20s) with ID and high	Mixed methods Qualitative – 'life stories' approach	To allow parents to report on experiences and outcomes of their young adults in post-	Purpose-designed postal survey to gather parental	Current life satisfaction reported positively ('much', 'a great deal') by 64% 13% indicated child not currently satisfied	Proxy reporting Response rate 27% Self-selected sample

		support needs who had completed school Drawn from schools (transition staff identified potential parents) Their children had: ID (N=182) ASD (without ID) (N=28) Dual diagnosis (ASD and ID) (N=30)	and Quantitative – postal survey	school transition	perspective on transition experience/outcomes	with life ('not at all', 'a little')	- highly motivated and well placed to communicate difficulties Level of ID not reported No comparison group 7
Rimmer et al. 2010	Across USA	N=461 Parents of children with mild to moderate ID Age 12-18 Recruited from multiple sources. Families were directed to visit Survey website Comparison group: data from 2007 Youth Risk Behaviour Survey (Centers for Disease Control and Prevention, 2008)	Cross-sectional	To explore prevalence of obesity and related secondary conditions (and compare to published data of youth without disabilities)	Purpose-designed web-based survey	Parents of adolescents with autism and Down syndrome 2-3 times more likely to have reported obesity than general population and to report secondary conditions eg high blood pressure/cholesterol, diabetes, depression, fatigue, low self esteem	Proxy reports may under-estimate obesity Non-representative sample – people who use the internet May be other secondary conditions (eg deconditioning, loneliness) not reported Potential bias in comparison group 7
Taylor & Seltzer 2010	Wisconsin and Massachusetts, USA	N=242 Mothers of children with ASD with/without ID Age 10-23 Recruited through service agencies, schools and clinics	Longitudinal	To examine whether exiting high school is associated with alterations in rates of change in autism symptoms and maladaptive behaviours	Self-administered questionnaires ADI-R Behaviour Problems subscale of the SIB-R	Autism symptoms and maladaptive behaviours were improving over time while young people were in high school, but les so for those with ID. Improvement in internalised behaviours stopped after high school exit, and improvement in	Volunteer sample skewed towards those with higher socioeconomic status Level of ID not reported

					Vineland Screener WRIT School record review	externalised behaviours became more pronounced after high school exit. Individuals with ID had more repetitive behaviours, verbal communication impairments, internalised behaviours and externalised behaviours	All participants had autism 8
Bhaumik et al. 2011	Leicester, Leicestershire and Rutland, United Kingdom	N = 79 Age 16 – 19 Recruited from mental health services, community paediatric services, social services, education services and Connexions service	Cross-sectional	To estimate the number of teenagers with ID age 16 – 19 and to estimate the number of these with significant mental and physical healthcare needs	Postal questionnaire including Vineland Qualitative interview with a sub-sample of 24 carers	86% had physical problems and/or mental health or behaviour problems and/or epilepsy On average teenagers used 5 different services, and carers reported that they needed 4 more	Level of ID not reported for questionnaire data No comparison group No data from teenagers or professionals 6
Forte et al. 2011	Scotland, UK	N=52 (ID N=26; non-ID N=26) Age 17-20 Mild ID (assessed by ABS) Recruited from a single Further Education College Had to have 6 months left on course	Qualitative – photographic materials to stimulate semi-structured interview Between groups Cross-sectional	To examine context/salience of worries experienced by young people with ID as they transition to adulthood	Semi-structured purpose designed 'worry' interview GSES – 12 GAS-ID	ID worries include being bullied, losing someone they are dependent on, failing in life, making/keeping friends ID worries based more on previous/current circumstances whereas non-ID based more on uncertainties regarding future. Higher rumination in ID group than non-ID group Higher distress in ID group than non-ID group Strong significant positive correlation (r = .76, p = .001) between distress scores and GAS-ID in ID group	Measures taken only at a single point in time Participants recruited from a single college No comparison group 8

Pownall et al. 2011	Scotland, UK	N=8 Mothers with 1 child with mild-moderate ID Age 17-19 and at least 1 child without ID (>5 years older/younger) Recruited through Enable (voluntary organisation)	Qualitative – semi-structured interview Cross-sectional	To contrast mothers' experiences of supporting sexuality in ID and non-ID siblings	Semi-structured interview	Themes: difficulty of striking a balance between independence and control; dependency of ID youth (few opportunities to socialise); difficulty adjusting to physical changes; vulnerability; parental control over sexuality	Small sample Sample biased towards higher functioning ID 8
Larkin et al. 2012	Scotland, UK	N=26 Mild to moderate ID Age 16-20 Recruited from two further education colleges Non-ID comparison group (N=20) Age 16-20 Recruited from two colleges, one youth club and one secondary school	Qualitative – semi-structured interview; content analysis	To investigate experiences of interpersonal conflict in young people with ID at transition, compared with experiences of non-ID young people	Semi-structured interview about recent experiences of interpersonal conflict CEBA interview WASI CCB	ID young people more likely to encounter conflict with strangers/peers outside friend group (over half described incidents of physical or verbal aggression) and to characterise other people globally as 'bad'; more likely to feel victimised	Socio-demographic differences between groups that could explain results eg ID group from more deprived backgrounds than non-ID group 8
Barron et al. 2013	London, United Kingdom	N = 27 Age 16 – 18 Mild ID N = 11 Moderate ID N= 11 Severe ID N = 5 Identified by a transition social worker	Cross-sectional	To examine the sociodemographic and clinical characteristics of young people with ID and challenging behaviour at transition to adult services, as well as pattern of service use and associated costs of care	Interview included SDQ, mini PAS-ADD, CSRI, CBCL	88% of the sample were living at home with parents or foster carers 24 individuals were in full time education 23 individuals had a mental health diagnosis (emotional disorder was the most prevalent) 18 had a physical diagnosis Mean total cost of all services per week was £2543	Participants were from an inner city service so the findings are not generalizable No comparison group 5
Biggs & Carter 2016	Tennessee, USA	N = 389 parents/caregivers of young adults with disability (age 13 – 21)	Cross-sectional	To examine the subjective health and wellbeing of transition age youth with	Postal survey including KIDSCREEN-27,	Parent reported wellbeing of youth with ID was significantly lower than for the normative sample in physical wellbeing (p	Proxy reports Level of ID not reported

		ID N = 157 Autism and ID N = 54 Recruited from family/disability organisations Normative comparison group N = 16,888 proxy respondents from European KIDSCREEN field survey		autism or ID	Santa Clara Strength of Religious Faith questionnaire, AIR self-determination scale, parent version ASPeCT-DD	< .0001), psychological wellbeing (p = .0002), and social support and peers (p<.0001) Lowest ratings were in social support and peers Having autism, high support needs or challenging behaviour was negatively associated with quality of life domains	8
Young et al. 2016	West of Scotland, United Kingdom	Adolescents with mild to moderate ID N = 25 Adolescents without ID N = 27 Age 15 – 18 Recruited from schools	Cross-sectional	To examine the content and emotional impact of worries amongst adolescents with and without intellectual disabilities at the time of leaving school	Background information sheet Worry interview GAS-ID WASI	Adolescents with ID were significantly more anxious than their non-disabled peers (p = 0.03) No significant difference between the two groups' level of rumination or distress was found Adolescents with ID were more concerned about death, relationships, bullying and decisions than their non-disabled peers Those without ID were more concerned about failure, family, college and money than those with ID	Those with severe/profound ID excluded Between groups analysis was underpowered 6

Table 1: Summary of articles (organised by publication date) (Young-Southward)

Abbreviations:

ABS: Adaptive Behaviour Scale

ADI-R: Autism Diagnostic Interview-Revised

ASPeCT-DD: The Assessment Scale for Positive Character Traits-Developmental Disabilities

ASD: Autism Spectrum Disorder

CCB: Checklist of Challenging Behaviour
CEBA: Cognitive Emotional Behavioural Assessment
CSRI: Child Service Receipt Inventory
DD: Developmental disability
F-COPES: Family Crisis Oriented Personal Evaluation Scale
GAS-ID: Glasgow Anxiety Scale-ID
GSES-12: General Self Efficacy Scale
ID: Intellectual Disability
LEA: Local Education Authority
MADDS: Metropolitan Atlanta Developmental Disabilities Study
MADDS-FU: MADDS Follow-Up of Young Adults
PAS-ADD: Psychiatric Assessment Schedule for Adults with Developmental Disability
QoL-Q: Quality of Life Questionnaire
QRS-F: Questionnaire on Resource and Stress – Short form
SDQ: Strengths and Difficulties Questionnaires
SIB-R: Scales of Independent Behaviour Revised
STI: Sexually transmitted infection
WRIT: Wide Range Intelligence Tet
WASI: Wechsler Abbreviated Scale of Intelligence
WJ-III: Woodcock-Johnson III

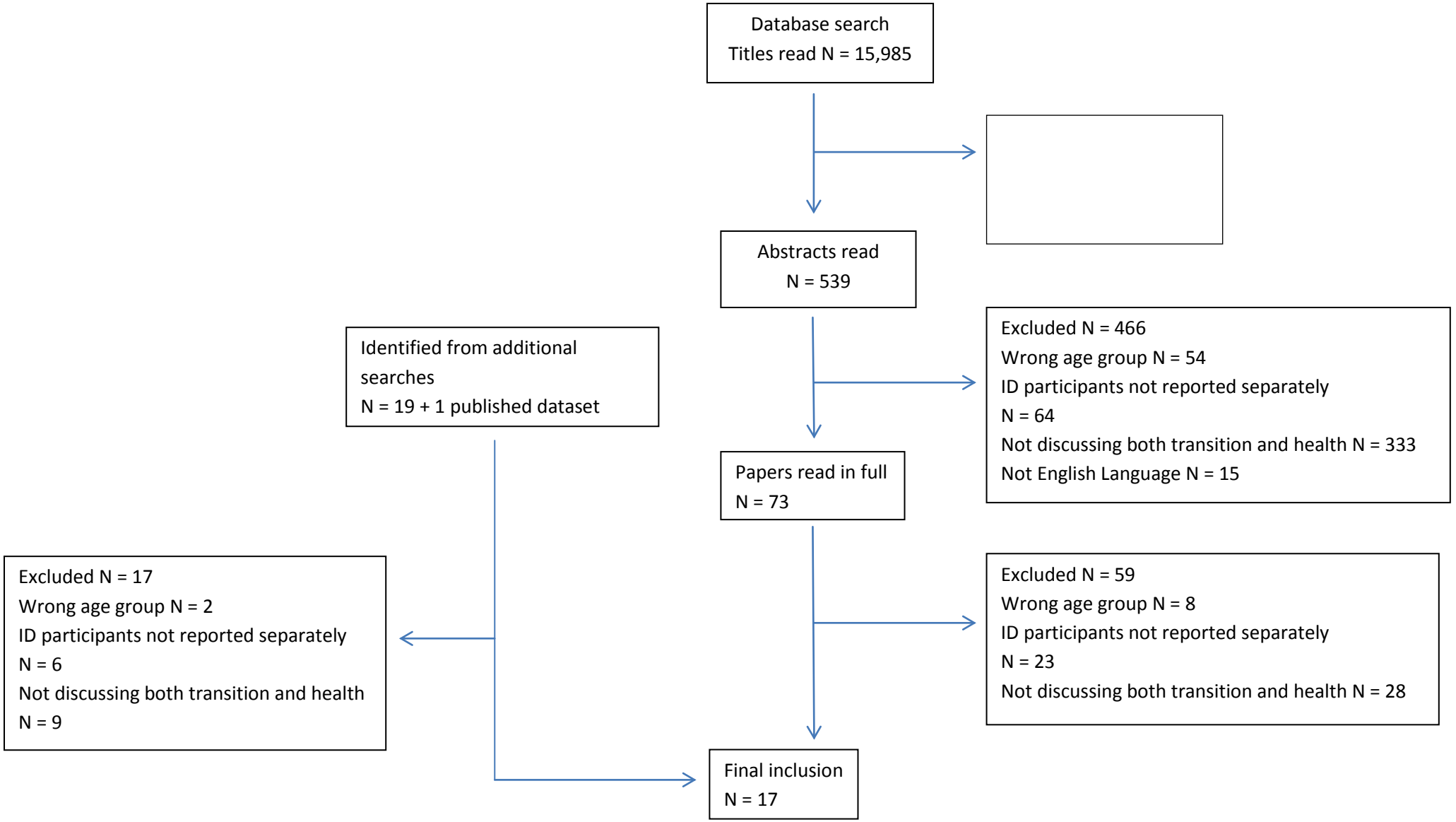

Figure 1: Inclusion and Exclusion of Articles (Young-Southward)